



Title	Perinatal bereavement: grieving pregnancy loss in miscarriage and stillbirth
Author(s)	Chan, CHY
Citation	The 8th Hong Kong Palliative Care Symposium, Hong Kong, 20 August 2011. In Newsletter of Hong Kong Society of Palliative Medicine, 2011, n. 2, p. 10
Issued Date	2011
URL	http://hdl.handle.net/10722/136539
Rights	Creative Commons: Attribution 3.0 Hong Kong License



Newsletter of Hong Kong Society of Palliative Medicine

Oct 2011 Issue No.2

<http://www.hkspm.com.hk>

Contents

- P2 Editor's Column
- P3 AGM & ASM of Hong Kong Society of Palliative Medicine 2011
- The 8th Hong Kong Palliative Care Symposium***
- P4 Report on 8th Hong Kong Palliative Care Symposium
- P7 Challenges for palliative care
- P9 Grief and bereavement
- P11 New challenges for palliative nursing
- P12 Volunteer work for end-of-life services
- P14 Free papers
- P19 Workshop on spiritual care in end-of-life
- P20 More photos from 8th Hong Kong Palliative Care Symposium
- P22 Report on 9th Asia Pacific Hospice Conference
- P25 A palliative experience with Amyotrophic Lateral Sclerosis
- P29 The stress and burden of caregiving
- P32 Palliative care of a patient with end stage renal failure and cancer
- P34 Management of malignant pleural effusion: A brief update
- P36 Membership Information
- P37 Education Seminars & Meetings
- P38 News from Society for the Promotion of Hospice Care



FROM THE EDITOR: ACP, SDM & SUSTAINABILITY

DR. DORIS TSE, EDITOR-IN-CHIEF

In this issue, readers will notice the frequent appearance of advance care planning as the theme of community involvement, education of elders and preparing for end-of-life (EOL). Advance care planning has been emphasized as a process of communication regarding end-of-life care options. The notion of a bilateral communication process in health care is not new. In 1997, Charles et al published a paper titled "Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango)", which has been cited extensively by now.¹ The authors described the key characteristics of shared decision-making (SDM) (1) it involves at least two participants—physician and patient; (2) both share information; (3) both take steps to build a consensus about the preferred treatment; and (4) that an agreement is reached on the treatment to implement. SDM has been advocated as an ideal model in medical treatment decision-making in medical encounters with patient-centered care as the ultimate goal.

SDM rests on the best evidence of the risks and benefits of the available options with different possible outcomes and substantial uncertainty. The process include ensuring patients' understanding of information, eliciting patients' preferences, sharing treatment recommendations, and making explicit the component of uncertainty in the clinical decision-making process.² There are now a large number of patient decision programs (decision aids) available and their use has been evaluated in randomised controlled trials. A Cochrane review has summarised the findings from 55 trials and found that use of patient decision aids led to:³

- greater knowledge
- more accurate risk perceptions
- greater comfort with decisions
- greater participation in decision-making
- fewer people remaining undecided
- no increase in anxiety
- fewer patients choosing major surgery

SDM has been regarded as "The Greatest Untapped Resource in Healthcare" in the Salzburg Global Seminar held in December 2010, and following that, the Salzburg statement on shared decision-making was published in *BMJ* in 2011 to stimulate attention.⁴ Ethically, patients should be involved more in decisions about their own medical care and the risks involved; practically it brings down costs through careful presentation of information and the use of decision aids/pathways. Unwarranted practice variations, but with no better outcomes, are reduced. SDM is therefore being promoted to deliver sustainable health care through patient centred care and patient empowerment. In UK, the National Shared Decision Making programme, led by NHS East of England, is designed to promote patient centred care and to enhance sustainability of care and the paper "Making Shared Decision-Making a Reality. No decision about me, without me" was published recently.⁵

If SDM is so good to adopt, why has it not become as popular as it should be? In a systematic review of 28 studies on the barriers and facilitators to SDM in health care professionals, the three most often reported barriers were time constraints, lack of applicability due to patient

characteristics and lack of applicability due to the clinical situation. The three most often reported facilitators were provider motivation, positive impact on the clinical process, and positive impact on patient outcomes.⁶

By now, readers would appreciate the similarity in the components of SDM and advance care planning (ACP). In SDM, the context is often related to treatment of life threatening illness or chronic diseases⁷; in ACP, it is about the preferred care at EOL. There is no obvious reason why barrier to ACP is less than that for SDM, as preparing for end-of-life is about overcoming barrier to discuss death and dying. Such barrier exists in the professionals, who often feel uncomfortable to address the apparent failing of medicine, and in patients, who are often not prepared to face the unknown of the dying phase.

The modern hospice movement as initiated by Dame Cicely Saunders is now more than 30 years on. While palliative care has flourished in many parts of the world since then, there are endless challenges to ensure the sustainability of palliative care development. From the English dictionary, to "sustain" means to keep in existence; to supply with necessities or nourishment; to support from below to keep from falling or sinking; to support the spirits, vitality and to encourage; to endure; to experience or suffer; to prove and confirm and to maintain competence. All these elements are not just essential to uphold the quality of palliative care, but also the health care system and the society.

Modern health care systems have been undergoing reforms to achieve sustainability. However, this would not be possible without reflections and critical evaluations. Data collection, not just on the volume and coverage, but also the outcomes has to be considered seriously. Inconsistency and lacking of clear concept or definition of a care model pose hurdles for critical analysis, such as the case of SDM, a term which has been used inconsistently in some research papers.⁸ It is encouraging to see growing attention to advance care planning in Hong Kong. However, there are many challenges ahead. It remains for palliative care professionals to define the structured components of the advance care planning process, the indicators of the processes and the outcomes. Critical evaluation of ACP sheds light on the sustainability of the palliative care development and also our health care system.

References

1. C Charles, A Gafni, T Whelan. Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango) *Soci Sci & Med* 1997;44(5):681-692.
2. C Charles, T Whelan, A Gafni, A Willan, S Farrell. Shared Treatment Decision Making: What Does It Mean to Physicians? *J of Clin Oncol* 2003;21(5):932-936.
3. O'Connor AM., Bennett CL, Stacey D et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2009, Issue 3. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431.pub2
4. Salzburg Global Seminar. Salzburg statement on shared decision making. *BMJ* 2011; 342:1745.
5. MAKING SHARE DECISION-MAKING A REALITY: No decision about me, without me. https://www.eoe.nhs.uk/page.php?page_id=2165
6. Gravel K, Légaré F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implement Sci* 2006;1:16..
7. S Desroches. Shared decision making and chronic diseases. *Allergy, Asthma & Clinical Immunology* 2010;6 (Suppl 4) :A8 doi:10.1186/1710-1492-6-S4-A.
8. N Moumjid, A Gafni, A Bre'mond, MO Carre're. Shared Decision Making in the Medical Encounter: Are We All Talking about the Same Thing? *Med Decis Making* 2007 27: 539.

ANNUAL SCIENTIFIC MEETING HONG KONG SOCIETY OF PALLIATIVE MEDICINE



Co-organisers

CENTRAL COMMITTEE ON PALLIATIVE CARE
HOSPITAL AUTHORITY



HONG KONG PALLIATIVE NURSING ASSOCIATION

PALLIATIVE CARE IN ADVANCED COPD CHALLENGES & DIFFICULTIES



Guest speaker:
Professor J Randall Curtis, M.D., M.P.H., F.C.C.P.

Professor of Medicine, Division of Pulmonary and Critical Care Medicine,
School of Medicine, University of Washington, Seattle, WA.
Section Head, Pulmonary and Critical Care Medicine,
Harborview Medical Center

Date: 9th Dec, 2011

Venue: Lecture Hall, M/F, HA Building

Time: 5:30pm Refreshment

6:00pm Annual General Meeting

6:30pm Lecture

CME CNE APPLIED

No registration required

ALL ARE WELCOME

SPONSORS



Report on 8th Hong Kong Palliative Care Symposium

*Dr. Chan Kin-sang,
Chair of Organising Committee*

The Symposium was held on 20 August 2011 at Hui Pun Hing Lecture Hall, The University of Hong Kong. The lecture hall was packed with enthusiastic faces. More than 300 healthcare professionals from various clinical settings attended. The program began with, on behalf of the organizing committee, Dr. Chan Kin-sang's warm welcome to all participants. We are honored to have Dr. Leung Pak-yin, Chief Executive of the Hospital Authority as our Guest of Honor for the opening ceremony. He made an encouraging speech sharing his insight on end-of-life care from a healthcare management expert's perspective.



*Left to right:
Dr. Chan Kin-sang,
Dr. Leung Pak-yin,
Prof. Cecilia Chan*



8th Hong Kong Palliative Care Symposium

20 August 2011

Organizer



善寧會

Society for the Promotion of Hospice Care

Co-organizers



HKSPM
Hong Kong Society
of Palliative Medicine

Collaborators



香港大學行為健康研究中心
Centre for Palliative Care



Honorable guests & organizers

More than 20 guest speakers were invited for the Symposium. The major themes of the Symposium include new challenges in palliative care: "Prognostic challenges for palliative care" was shared by Dr. Lam Po-tin, "Reflection on palliative care for advanced cancer patients in the age of targeted therapy" by Dr. Rebecca Yeung, as well as "Ethical dilemma for tube feeding in advanced dementia patients" by Prof Samantha Pang. The session was very stimulating and called for our reflections. Moreover, the theme on Grief and bereavement were shared by Dr. Celia Chan and Dr. Amy Chow on "Perinatal bereavement: Grieving pregnancy loss in miscarriage and stillbirth" and "Intervention model with older adults coping with grief & loneliness" respectively.



We were pleased to have received a record high of abstract submissions for the freepapers session. It was a tough task for the adjudicators, Dr. Wong Kam-hung, Dr. Rico Liu and Ms. Leung Man Wai to select the two outstanding awards from 13 contestants. Congratulations to Dr. Poon Yin of CMC and Ms. Theresa Lai of PMH.

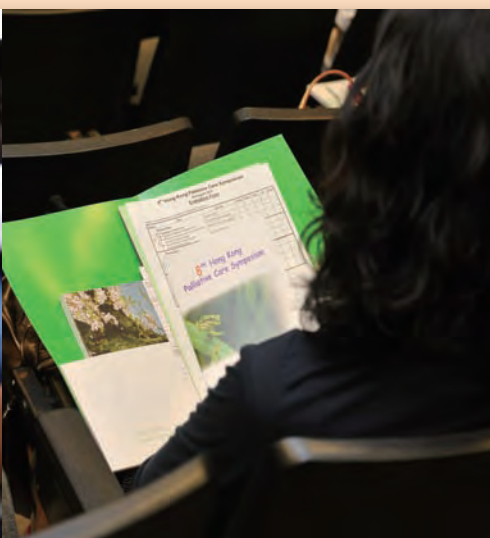


Dr. Wong Kam-hung & Ms Theresa Lai, awardee of outstanding presentation in Free Paper Session



Dr. Rico Liu & Dr. Poon Yin, awardee of outstanding presentation in Free Paper Session

Besides the free-papers, there were three other afternoon concurrent sessions, all with a unique perspective. “Volunteer work for end-of-life care services” was a theme discussed, where “Volunteers in supporting the dying in hospital” was shared by Ms. Ellen Yeung and RH-TSKH volunteers. A drama on Advance Care Planning was performed by 3G Alumni of SPHC to prelude the sharing of “Engaging volunteers in community outreach program on Advance Care Planning” by Ms. Carol Cheng and Ms. Betty Fung. “New Challenges for Palliative Nursing” is the theme for the nurses’ session. Cases on “Non-cancer end-of-life care” were shared by Ms. Cecilia Kwan, Ms. Chiu Pui Chi, Ms. Kwan Yuen Fan, Ms. Mak Kit Nga, while “Advance Care Planning” was shared by Ms. Chan Chun Hung. There was also a workshop conducted by Dr. Rhoda Yuen on “Spiritual care at the end of life”.



Ethical dilemma for tube feeding in advanced dementia patients

Prof. Samantha PANG

Professor and Head, School of Nursing, The Hong Kong Polytechnic University

Eating problems commonly present during the final stage of dementia. Either placing a feeding tube or forgoing the tube in this population poses ethical dilemma to care providers. On one hand, tube feeding is a common approach despite consistent clinical review reports found no demonstrable benefits in terms of key outcomes such as prolonged survival or improved nutritional markers. On the other hand, marked variation in tube feeding exists across different places. Studies on places with high and low tube feeding practices varied in their institutional values, health professional values, physical environment, care processes for feeding, and decision making approaches. Forgoing tube feeding is controversial from an ethical-clinical viewpoint. It can deliver sufficient nutrition and hydration to support the patient's life hence a basic sustenance care which should always be in place; yet it fails to improve the underlying incapacitating condition which put into question its medical benefit. Such decision-making would inevitably be value-based and emotionally-laden.



Prof Samantha Pang & Dr. PY Leung, CE, HA



Prof Samantha Pang & Prof. Cecilia Chan

advanced dementia would be remote. In this presentation, I will take a virtue ethics perspective to examine the possibility of agreement of what counts as good and harm in tube feeding decision making, focusing on the telos (or ends) of the care provider and patient relationship.

Before whatever else we should do no harm to others is the ethical mandate that care providers are obliged to observe in service provision, yet what counts as harm to others in a pluralistic community where people do not agree on the same set of fundamental values yield competing clinical implications. From the human rights perspective, care providers who fail to respect the patient's rights would count as harm. Drawing on the duty-driven dignitarian view, an act that compromises human dignity would count as harm. An act is right if it can maximize health and happiness from a utilitarian perspective, hence harm to others would be performing an act which its negative consequence outweighs the positive consequence. Given the disagreement on these fundamental values, the possibility of resolving the conflicting views on tube feeding or not patients with



Panel discussion: (From Left to right)
Dr. Doris Tse, Dr. PT Lam,
Dr. Rebecca Yeung,
Prof Samantha Pang,
Prof. Cecilia Chan

Perinatal bereavement: Grieving pregnancy loss in miscarriage and stillbirth

Dr. Celia CHAN H.Y.

Teaching Consultant, Centre on Behavioral Health
Honorary Lecturer, Department of Social Work and Social Administration,
The University of Hong Kong

Many couples have experienced the death of a baby. It could happen during pregnancy, during delivery, shortly after birth, or during infancy. Some are unexpected: in spite of medical advances, more than one-fifth of all expectant parents will at some time experience miscarriage, stillbirth or infant death. For some other couples, early termination, whether of unwanted pregnancies due to personal choice or of wanted pregnancies due to medical reasons, is carried out at their own decision.

A couple's experience of loss in miscarriage and stillbirth is not easily shared by others – "but it wasn't even a baby yet." The lack of clarity of the loss (in the absence of a touchable, separate infant's body) is the reason for many who find it difficult to appreciate the full extent of grief in pregnancy loss. Couples who have miscarriage and stillbirth are also confused about their bereavement experience and sometimes not sure about how to react. As a result, many of them choose not to seek help and support from their family and friends; the couple does not know how to name the grief, neither do those who are close to them know how to respond.

In Chinese societies, expectant mothers do not disclose their pregnancy during the first trimester for the traditional fear that it would jinx or 'upset' the

baby, who would then 'refuse to be born'. Pregnancy loss during this early stage, while not uncommon, will be a secret within a secret, further complicating the grief process.

In essence, pregnancy loss due to miscarriage or stillbirth is always considered as disenfranchised grief over an ambiguous loss. Cultural considerations are important in helping the Chinese couples who are facing the losses.



Dr. Celia Chan at her presentation



Panel discussion: (From left to right) Ms Leung Man Wai, Dr. Annie Kwok, Dr. Amy Chow, Dr. Celia Chan

Grief and Bereavement

New Challenges for Palliative Nursing

End-of-life care for non-cancer patients

Ms. Cecilia KWAN,
Ward Manager, Bradbury Hospice
Ms. CHIU Pui-chi, Ms. MAK Kit-nga,
Advanced Practice Nurses, Haven of Hope Hospital
Ms. Piana KWAN Y.F.,
Registered Nurse, Bradbury Hospice & Shatin Hospital



Current development of palliative care has extended to patients with advance diseases other than cancer. Patients with organs failure like end stage renal disease (ESRD), chronic obstructive pulmonary disease (COPD), heart failure, and even dementia and stroke are relatively new to palliative care nurses. To take good care of these types of patients and to ensure effective symptom control and end-of-life support is a challenge for many nurses who used to look after terminal cancer patients.

These patients present with symptoms not exactly like those of cancer patients. End stage chronic kidney disease patients without dialysis present a number of physical symptoms like edema, pain, nausea and vomiting, bowel and bladder problems, lethargy, dyspnoea and pruritus. Patients with chronic liver disease present with severe pain, pruritus, ascites, hepatic encephalopathy and sometimes variceal hemorrhage. COPD patients might suffer much from

dyspnoea, fatigue and cachexia. The causations of these symptoms are different requiring different way of interventions and nursing support. The use of drugs to relieve pain, edema, nausea and vomiting are considered differently from those for cancer patients. The associated nursing observation and support requires adjustment.

The psychological, social and spiritual needs of these patients are no less than cancer patients. Feelings of depression, social isolation, and burden to family are common among patients at end-of-life stage no matter what the diseases are. The holistic approach of palliative nursing renders important support to these patients. However, the disease trajectories may vary among these terminal illnesses. Advanced cancer and ESRD patients may present with slow deterioration while patient with heart failure might risk a sudden death. All these have impact on the fine tuning of the approach of care. The discussion on disease progression, advance care planning and reassurance of continual support formulate important element of nursing interventions.

Advance Care Planning

Advance care planning (ACP) is the process of planning for future medical care, particularly for the event when the patient is unable to make his or her own decisions. During this process patients explore, discuss, articulate, and document their preferences. The process helps patients to identify and clarify their personal values and goals about health and medical treatment. They identify the care they would like, or not like, to receive in various situations.

The model for ACP can be applied to other decision-making processes as patients plan for the end of their lives (e.g., planning for bequests,



Ms. Red CHAN C.H.,
Advanced Practice Nurse, Tuen Mun Hospital

autopsy, burial / cremation, funeral/ memorial services, guardianship, choices of caregivers, and settings for care).

It is helpful to think of the process as a stepwise approach. The steps include the appropriate introduction of the topic, structured discussions covering potential scenarios, documentation of preferences, periodic review and update of the plans and directives, and application of the wishes when needed. The steps can then be flexibly integrated into routine clinical encounters by the members of the health care team. The process fosters personal resolution for the patient, preparedness for the carer, and effective teamwork for the professionals.

Volunteer Work for End-of-life Services

Volunteers in supporting the dying in hospital

Ms. Ellen YEUNG Wai-fong
Hong Kong Palliative Nursing Association
Palliative Nurse Specialist,
Ruttonjee & Tang Shiu Kin Hospitals

Volunteers have always been the core of any palliative program. They generously offer their time talents and energy. They offer terminally ill patients and their families comfort, support, and companionship. Palliative volunteers are important members of an interdisciplinary team, serving to “de-institutionalize” the dying experience and provide a more humane system of care for the dying and their families. Palliative volunteers have challenging jobs, which may include hospital and home visits, family care, administrative support, help with day programs, special events and celebrations, bereavement support and the list goes on. Each person brings a unique mix of talents and interests to the palliative experience and each volunteer is needed and appreciated by everyone in the palliative community. Volunteers in palliative setting find it personally gratifying, intellectually stimulating, and emotionally meaningful to assist those in need at a critical point in their lives. Many of these volunteers were introduced to palliative services through the death of a family member and understand firsthand the value of palliative care. Volunteers consistently report that helping the terminally ill is not about dying but about living and they find that it brings meaning and purpose to their lives.



Ms. Ellen YEUNG Wai-fong & Mrs Yvonne Siu



Workshop participants in small group discussion

Engaging volunteers in community outreach program on advance care planning



Mrs Yvonne Siu, Ms Carol Cheng & Betty Fung

Ms. Carol CHENG Chit-yan
Education Officer, Society for the Promotion of Hospice Care
Ms. Betty FUNG Pei-tai
Community Education Officer,
Society for the Promotion of Hospice Care

Advance Care Planning (ACP) is a process of improved understanding, reflection, and discussion to create a clear plan, formulated in advance to guide medical and health care decisions if the ill person is unable to make decisions. This process takes into account the person's health condition, culture, relationships as well as his or her goals and values. ACP is a complicated but useful process to empower people to plan proactively for an improved quality end-of-life care.

Sponsored by Lee Hysan Foundation, the ACP project aims to support older adults in the community to actualise ACP in a systematic manner and territory-wide outreach. In 2008-2011, ACP project reached over 2,000 elders, family members, volunteers and care workers. In this project, the role of volunteers is significant. The volunteer management strategy can help in effective operation which includes planning, recruitment, training, supervision and recognition. The components are playing its integral functions to make a successful volunteer teamwork possible.

Drama on Advance Care Planning

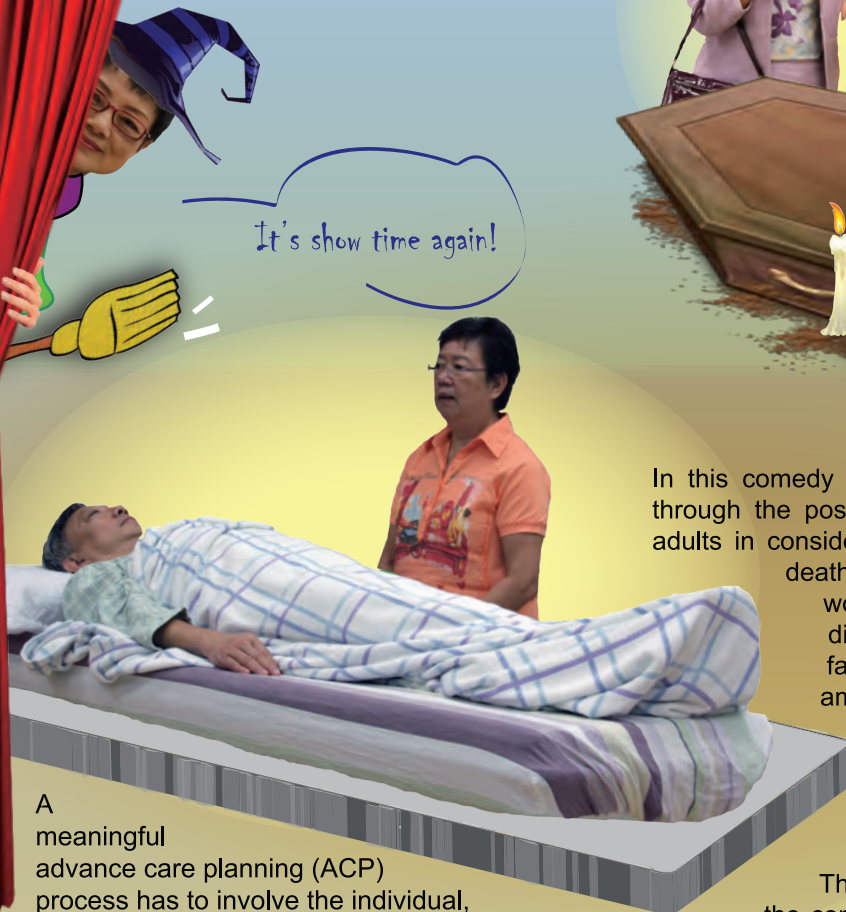
Ms. Rosa LEUNG, Ms. TSE Mei-wah, Mr. Michael NG
Mr. Tony KWAN, Ms. Karen WONG, Ms. Barbara HO
3G Alumni, Society for the Promotion of Hospice Care

About 3G Alumni Drama Team

3G Alumni is the natural formation of SPHC's 3G Quality Retirement Program. This is a life & death education (LDE) program targeting the retired professionals. 3G represent "Look Good, Feel Good & Do Good". Steered by Mrs. Yvonne Siu, member of SPHC's Executive Committee, this program is devised in response to the aging population using young old serving the old old. Beside the LDE content, members participate in holistic learning to grow old as well as are equipped with the knowledge and skills to serve others. In serving others, it is also a learning process for the retired to augment the altruistic human nature. The Alumni is a self-directed group with vibrant qualities. 3G Alumni Drama Team is one of the five vitality teams created by the members to serve the community.



未到生死也相安



In this comedy section, the 3G Alumni would help us walk through the possible concerns and perceptions of the older adults in considering ACP. Through the use of humour, this deathbed scene is acted out as an exaggerated worst possible outcome of little advance discussion or planning on end of life care among family members. This is an open dialogue among peers, touching on some challenges and dilemmas of facing death and dying. With the professional directing advice from Mr. James Mark, who is also a member of the 3G Alumni, this comedy section is created by members of 3G Alumni's drama team. They have this creation due to their exposure to the content of life & death education from SPHC as well as in serving the elders in their "Do Good" community service.

A meaningful advance care planning (ACP) process has to involve the individual, their family members and the healthcare professionals. In considering the individual's ACP, the person would have many personal issues, thoughts and feelings surfaced. Moreover, many older adults in considering ACP find that the most challenging part is to involve the family members.

I am not ready to die yet!



Volunteer work for end-of-life services



Free Paper Presentation

8th Hong Kong Palliative Care Symposium

Evaluation of the Responsiveness of Goal Attainment Scaling in the Measurement of Oncology In-Patients under Physiotherapy Treatment

LIU Yuet-ming*, M.Y.C. PANG

*Physiotherapist I, Physiotherapy Department, Princess Margaret Hospital

Background

There is a lack of a responsive evaluation tool for measuring the progress of the frail oncology inpatients undergoing physiotherapy intervention. Although Barthel Index (BI) has been used, its responsiveness has been challenged.

Objective

- 1) to assess the inter-rater reliability and responsiveness of Goal attainment scaling (GAS) in oncology inpatients who were undergoing physiotherapy
- 2) to compare the responsiveness of GAS with BI.

Method

A total of 38 oncology inpatients (22 men and 16 women), with mean age \pm SD = 65.63 \pm 13.75 were recruited. They were scored with GAS and BI before and after completing 3-day of physiotherapy intervention. 10 subjects were randomly selected to receive another post-treatment scoring for the establishment of inter-rater reliability. The pre-test and post-test scores of GAS (T-score) and BI were compared by using paired t-tests. Effect sizes (ES), standardized response means (SRM) were used to determine the responsiveness while relative efficiency (RE) between GAS and BI was used to compare their responsiveness.

Results

High inter-rater reliability were reflected in the ICC (2,1) = 0.98. Moreover, ES (1.51), SRM (0.87), and RE (214) of GAS were significantly greater than the corresponding values of BI (ES=0.04, SRM=0.06, RE=1). After 3 days of physiotherapy treatment, GAS score ($p < 0.001$, 95% Confidence interval = 5.74 -14.34) was significantly increased, but not BI ($p=0.75$, 95% confidence interval = 4.93 - 6.79).

Conclusion

The results showed that the GAS has high inter-rater reliability and it shows better responsiveness than BI. GAS is thus a useful tool for measuring changes in functional outcomes in oncology inpatients.

Health Care Staff's Perception of End-of-life Care in a Local Adult Intensive Care Unit

Jasmine CHAN T.M.*, K.L. LEE

*Resident Specialist, Department of Medicine & Geriatrics, United Christian Hospital

Background

Death in the Intensive Care Unit (ICU) is often inevitable. Nowadays, more emphasis is given on improving the care of dying patients and their families in ICU. Better understanding of health care staff's perception of end-of-life (EOL) care could facilitate its development in the future.

Objective

To examine the perception of medical and nursing staff who work in an adult Intensive Care Unit of a regional hospital on end-of-life care.

Method

This is a cross-sectional questionnaire survey. Health care staff's perception was assessed over 5 domains of quality end-of-life care in ICU setting.

Results

A total of 78 questionnaires were sent, the response rate was 70%. Majority of the respondents agreed (65%) that life-sustaining treatment is forgone in a way that patient or family's preferences are respected. Two third of the respondents also agreed that decision within the health care team is clearly communicated with patient or family. However, only 38% thought that they are confident in handling conflicts or intense emotions of the patient and family. It is associated with training in EOL care ($p < 0.05$) but not duration of ICU experience. Although 64% respondents felt competent in advising comfort care and symptom management, they admitted that it is psychologically more comfortable to withhold than withdraw life-sustaining treatment. Among the domains of quality EOL care, communication was ranked as the most important area.

Conclusion

End-of-life care is given attention in the Intensive Care Unit. More training and education on this management aspect is warrant, particularly to enhance psychological care and communication skill of health care staff.

Cross Sectional Study on the Desire for Hastened Death among Hong Kong Chinese Patients with Advanced Cancer in an Acute Hospital

CHEUNG Wai-yin*

*Resident Specialist, Department of Medicine & Geriatrics, United Christian Hospital

Background

Being a common phenomenon in the palliative care setting, the desire for hastened death (DHD) among patients with advanced cancer has not been studied in Hong Kong.

Objective

This cross-sectional study serves to investigate the prevalence and the correlates of DHD in Chinese

patients with advanced cancer in an acute regional hospital.

Method

Standardized measurement tools including the Desire for Death Rating Scale (DDRS), Hospital Anxiety and Depression Scale, Herth Hope Index, Memorial Symptom Assessment Scale and Norbeck Social Support Questionnaire were used to assess consenting participants.

Results

High DHD was reported in 38% of subjects. Strong correlation was shown between DDRS scores and markers of depression, hopelessness and physical symptom distress. Patients with tertiary education or above also reported significantly higher DHD. By logistic regression, depression and hopelessness were shown to be predictive of high DHD.

Conclusion

The desire for hastened death in advanced cancer patients is significantly correlated with depression, hopelessness and physical symptom distress. Further studies are needed to investigate on the mechanisms and possible rooms for the intervention of these factors in managing DHD of Chinese cancer patients.

Systems Dynamics in the Community Care Pathway at the End-of-Life:: the Hong Kong Experience

Michelle TAM Y.J.*, C.L.W. CHAN, J.K.H. LUK, F.H.W. CHAN, C.W.K. CHAN, C.H.C. FONG, A.H.Y. HO, C.K.K. KWOK, W.C. NG, J.H.L. YUEN

*Research Coordinator, Centre on Behavioral Health, the University of Hong Kong

Background

Since 2009, the HKWC-CGAT in collaboration with TWGHs JC C&A Home piloted the "EOL Program for RCHE in HKWC" program. The program offered 2 EoL care pathways on top of existing care framework: 1) AED pathway: residents remain in RCHE during last stage of life and stay there until very last moment of life; 2) FYKH pathway: resident be transferred to the hospital via expedite pathway at the last moment of life to receive hospice and palliative care until he/she passed away. The program has served 32 residents, 9 have chosen the AED pathway and two passed away peacefully in 2010. Success of this program highlights the need to examine interplaying factors in EoL care pathway and reflect on practical implications for quality EoL care.

Objective

To identify system factors that contributes to EoL care decision making and dignified EoL Care Pathways.

Method

This is a qualitative study with individual interviews and focus groups conducted. Participants was

purposively sampled, focusing on key participants in the EoL program: residents who participated in the scheme; family members; medical and allied-health staff; and administrative staff.

Results

Preliminary findings revealed themes that affect implementation of the EoL program: 1) information about the EoL program; 2) trust between family members and healthcare system; 3) readiness of RCHE staff; and 4) communication between the different parties.

Conclusion

Comprehensive EoL care should address needs of multiple parties operating at different levels. Trust and communication within the system is key to a successful EoL care pathway.

The End-of-life Profile of Advanced Cancer Patients in a Palliative Care Unit: Highlights from the End-of-life Care Pathway

POON Yin*, D.M.W. TSE, K.H. NG, O.L. KWOK, M.H. KHEMLANI, K.W. WOO, W.S. YAU

*Resident, Palliative Care Unit, Caritas Medical Centre

Background

A modified end-of-life (EOL) care pathway based on the Liverpool Care Pathway for the dying (LCP) - Multidisciplinary Team End of Life Care Pathway (MDTEOLCP) was launched in Palliative Care Unit (PCU) of Caritas Medical Centre (CMC) since 2010. It is used as a guide to provide care and support for the dying and caregivers.

Objective

To assess the symptoms, medication profile, and the psycho-spiritual needs of patients and caregivers at EOL.

Method

This is a retrospective chart review of patients who died in PCU of CMC with implementation of MDTEOLCP from 1st June, 2010 to 31st March, 2011. Descriptive statistics was used to assess the prevalence of symptoms, medication pattern, and psychosocial and spiritual needs.

Results

A total of 109 patients were analysed, among which 76% died within 72 hours of initiation of MDTEOLCP. The physical symptoms profile as documented in the MDTEOLCP included urinary problems (87%), cachexia (68%), dyspnoea (59%), death rattle (37%) and pain (24%). The most commonly drugs that were prescribed preemptively included analgesics (72%), antipyretic (31%) and haloperidol (19%); whereas the most commonly used drugs were oxygen (91%), analgesics (72%), hyoscine butylbromide (39%), antipyretic (25%) and haloperidol (24%). Five patients were given palliative sedation. There was rapid decline of food intake and conscious level from 72

hours before death, but with no associated increase in Ryle's tube insertion. Family members were interviewed by medical social worker in 49% of patients within last week. Urgent referral for psychosocial interventions was initiated in 7 patients. In 52% of patients, family had ever stayed overnight and in 65%, family was present at death.

Conclusion

Advanced cancer patients had considerable symptoms at EOL, with dyspnoea more prevalent than pain. The medications used may guide the preemptive prescription in facilitating timely symptom control. The EOL care pathway can provide a database to reflect the profile and needs of the dying patients.

An Audit of the End-of-life Care Pathway in a Non-cancer Palliative Care Setting

Tracy CHEN W.T.*, W.M. WONG, C.K. MOK

*Associate Consultant, Department of Medicine & Geriatrics, Tuen Mun Hospital

Background

Majority of deaths in Hong Kong occur in public hospital. Chronic non-cancer illnesses account for most of the deaths. An End-of-life Care Pathway (ECP) based on the recommendation in Liverpool Care Pathway for Dying Patient (LCP version 12) was developed. It was the first ECP applied to non-cancer setting in the M&G Department TMH.

Objective

To evaluate the standard of care for dying patients and to benchmark our performance with the National Care of the Dying Audit – Hospital (NCDHA) 2009 in UK.

Method

The pilot of ECP in the non-cancer palliative care unit TMH began at 1st Aug 2010. A retrospective audit was done to gather the ECP data from 1st August to 31st December 2010. Standard of care for dying patients was developed based on the latest version of LCP. Comparison of the ECP with NCDHA 2009 was made to evaluate the standard of care in our unit.

Results

A total of 117 deaths occurred in the audit period and 42 ECP was applied (34%). The median duration in ECP is 62 hours (IQR = 18 – 103). The results were compared with NCDHA 2009. Higher percentage of overall achievement was noted in our ECP. The average percentage of achievement was 86.6% in ECP vs 58.7% in NCDHA 2009.

Conclusion

The use of ECP provides a foundation for good symptom control, spiritual, psychological, social and spiritual support. Higher percentage of achievement was noted in most areas compared with NCDHA. Continuous staff education and supervision are required to further improve the ECP recruitment rate and performance in those weaker areas.

Symptom Profile and Control in Patients with Advanced Pulmonary Diseases Receiving Palliative Care

Jeffrey NG S.C.*

*Resident Specialist, Pulmonary and Palliative Care Unit, Haven of Hope Hospital

Objective

This retrospective study aims to review the symptom profile of the patients with advanced pulmonary diseases referred to a palliative care program, and the control of symptoms upon follow-up.

Method

Patients with clinical evidence of severe pulmonary diseases were referred for the program. They were routinely assessed in the first two palliative consultations for symptom profile with a checklist of sixteen symptoms and an extra free-entry item, using categorical scale (none, mild, moderate or severe). The single most distressing symptoms were recorded. Improvement was defined as a shift in symptom scale upon the second assessment.

Results

From July 2010 to April 2011, totally 75 patients were recruited. There were more male (82.7%) patients, of mean age 77.2 and median palliative performance scale (PPS) of 60%. Thirty-seven patients (49.3%) died, with mean length of service being 92.6 days. There were 55 patients who completed the first assessment, and 40 successfully did the second. The majority (90.7%) had a primary diagnosis of chronic obstructive pulmonary disease.

The most distressing symptom was dyspnoea (70%), followed by dry mouth (10%), pain (6%) and insomnia (6%). The control of these symptoms was reported: dyspnoea (17.6% improved, 67.6% static), dry mouth (36.7% improved, 56.7% static), pain (42.9% improved, 47.6% static) and insomnia (43.5% improved, 39.1% static). The most prevalent symptoms were dyspnoea (87.5%), tiredness (76.8%), dry mouth (73.2%), cough (60.7%), insomnia (53.6%), pain (50%) and urinary disturbance (50%).

Conclusion

Symptoms prevalence is high in patients with advanced pulmonary diseases. Our findings suggest that active palliative intervention can be effective in symptom control for these patients.

Quality of Life among Hong Kong Chinese Patients with Malignant Brain Tumour during the End of Life Phases

Josephine Cheung M.Y.*, V.Y.H. TANG, S.K.S. NG, C.K.Y. LAU, D.T.M. CHAN, W.S. POON

*Psychologist Assistant, Department of Surgery, Neurosurgery, The Chinese University of Hong Kong

Background

Handling dreadful news with patients who have advanced malignant brain tumour is not ever easy or straightforward. Standard treatment consists of surgery, radiotherapy, with or without chemotherapy, yet the treatment outcome and prognosis are not promising in terms of extending life expectancy. Patients and significant others are overwhelmed by uncertainties, as well as the issues of death and dying. They are generally under an enormous level of distress and discomfort which may have an impact on their quality of life (QoL).

Objective

This study focused on examining the quality of life in a clinical setting for advanced malignant brain tumour patients during their end of life phases. The measures assessed physical, social, emotional, role and cognitive functioning among patients.

Method

Standardized questionnaires of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire, Core 30 and Brain Cancer 20 module (ECORTC QLQ - C30 and QLQ - BN20) were employed. Twelve patients (mean age of onset 47; 7 males and 5 females) diagnosed with malignant brain tumours were recruited at the Prince of Wales Hospital during the phases of (i) pre and post operational treatment (n = 9), (ii) pre and post concomitant chemo-radiotherapy (n = 6), and (iii) pre and post radiotherapy alone (n = 4).

Results

The global quality of life remained rather stable throughout the different phases, and no significant difference was evident. However after the concomitant chemo-radiotherapy, patients had significant improvement in social functioning ($p = .015$, $\eta^2 = .72$) and reported a significant decrease of physical pain ($p = .045$, $\eta^2 = .46$). For those who received radiotherapy alone, the decrease in the subjective report of physical pain also reached a marginal significance level ($p = .058$, $\eta^2 = .75$). This could be interpreted as a trend for positive improvement.

Conclusion

This study showed preliminary findings on patient's quality of life throughout the end of life phases among the group of malignant brain tumour patients. Focusing on the medication such as pain relief, providing proper psychological counseling, encouraging social life among family members and instructing stress management skills could enhance and facilitate the true meaning of "active living".

Searching for Spiritual Peace:

A Case Example of Life Integration and Relationship Reconciliation in the End-of-Life

Pearl TSE M.Y.¹, Candy FONG H.C.², P.P.Y. LEUNG,

P.O.K. NG, J. LEUNG, R.S.K. LO, C.L.W. CHAN

¹ Togetherness

²Miss Candy FONG Hio-cheng, Research Coordinator, Centre on Behavioral Health, the University of Hong Kong

Many patients approaching the end of life are confronted with spiritual concerns related to a sense of personal integrity, meaning of life, and a fulfilled past. This presentation uses a case story to present how a qualitative study can be integrated with community intervention in helping patients searching for spiritual peace in their end of life.

Three semi-structured interviews were conducted with the case who was a male older adult receiving palliative care in Sha Tin Hospital, Hong Kong. Findings reveal that a sense of self integrity through fulfilling familial responsibilities, seeking forgiveness and reconciliation of significant relationships are important themes contributing to the patient's spirituality. As a follow up of the qualitative study, a charity organization in Hong Kong, Togetherness, provided a life review and meaning-making intervention in helping the patient to search for spiritual peace. Volunteers of the organization visited the patient and provided intervention with the following focuses: (1) **Life Integration: Revisit and reinterpret regretful life experiences focusing on what is learnt from these experiences and the meaning of life;** (2) **Relationship reconciliation: Visit mother's tomb, express love, gratitude and seek forgiveness from family, and family photo taking;** (3) **Living in the moment: Participate in social gatherings such as birthday party and festival celebrations and develop photography as new hobby.** The intervention is successful in regaining a sense of personal integrity, connectedness, and spiritual peace.

The Effectiveness of the Spiritual Care Group for Promoting Spiritual Health to the Frail Elders in Nursing Home

Daniel LAW H.Y.*, K.K. LO, W.T. LEE, K.W. LI, M.Y. CHAN, K.P. WAN

Objective

To examine the effectiveness of spiritual care group in improving the spiritual quality of life of frail elders.

Method

Under a hospice care program, twenty residents with Chinese version of the Mini-Mental State Examination (CMMSE)(Chiu et al. 1994) scored over 22 were recruited in Hong Kong Sheng Kung Hui Nursing Home and were randomized into experimental and control group, each with ten subjects. The experimental group received eight sessions of spiritual care group while the control group received eight sessions of general social activity in eight weeks. The Spirituality Part of Body-Mind-Spirit Well-Being Inventory (BMSWBI) (Ng et al. 2005) was

administered to assess their spiritual quality of life. Measurements were taken before and after the intervention.

The spiritual care group has eight sessions. Through meditation, breathing, body scanning, one-minute health techniques (Chan 2006), mindful eating and life review, group members' serenity, gratefulness, self assurance and ability to let-go are developed. As a result, the members' spiritual quality of life is improved.

Results

In the spiritual care group, group members were facilitated to learn and to practice forgiveness and gratefulness, and also to demonstrate a moderate state of mind and inner harmony.

Mann-Whitney Test was used to analyze the data collected through the Body-Mind-Spirit Well-Being Inventory (BMSWBI), it is shown that the experimental group (score change = +22.2) has a significant improvement of spiritual quality of life when compared to the control group (score change = -5.9) ($z = -3.79$, $p < 0.05$).

Conclusion

This study provides preliminary evidence that spiritual care group can improve the spiritual quality of life of dependent elders. The experience of that spiritual care group sheds light on developing a new approach in improving spiritual quality of life in hospice care in Hong Kong.

Meaning-focused intervention for advanced cancer patients

Theresa Lai T.K.*, E. MOK

*Nursing Officer, Department of Oncology (Palliative Care), Princess Margaret Hospital

Objective

The objective of this study was to explore the impact of a brief, individualized meaning-focused intervention for advanced cancer patients.

Method

This study employed a single blinded randomized controlled trial design with intervention and control groups, and measures taken at baseline, immediately after intervention, and one week after intervention. Quality-of-life concerns in the end of life questionnaire (QOLC-E) will be used as the measurement. There are 2 sessions for the intervention. Baseline measurement will be performed before the intervention. The first session involves a semi-structured interview that facilitates the search for meaning. The second session is to review, verify, and clarify the findings from the first session with the patients. The second and third measurement will be held one day and two weeks after the intervention for outcome measurements.

Results

The score of existential distress domain, quality of

life and overall scale of QOLC-E of meaning-focused intervention group were significantly higher than the control group. The results showed significantly improve quality of life in existential distress domain of meaning-focused intervention group. In addition the negative emotion domain, support domain, value in life domain, existential distress domain, quality of life and over scale of QOLC-E of intervention group improved after intervention. Apart from the improvement in the intervention group, support domains of both groups in the third measurement were improved after the study.

Conclusion

The findings of this study showed the brief meaning-focused intervention helps improve existential wellbeing and quality of life of advanced cancer patients.

Challenges of families living with frail older persons at the end of life

Ada Lau T.Y.*, S.M.C. PANG, D.C.N. YAU, Y.M. WU, K.S. CHAN

*Advanced Practice Nurse, School of Nursing, The Hong Kong Polytechnic University

Objective

Sustaining home care for frail older persons at their final days is an ideal situation. This paper focuses on the narratives of families as they reflect on the care challenges in sustaining home care for frail older persons at the end of life and expound how the family caregivers address the issues along the illness trajectory.

Method

An interpretive phenomenological approach was used. Individual interviews of fourteen family caregivers who planned to continue the care of frail older family members at home after discharge from hospital were conducted. They were further followed up at one month and three months after the first interview for any change of care preferences.

Results

Nine out of the fourteen frail older persons died in hospital during six months of the study, seven required institutional care and four died without utilization of old age home. Four themes emerged: (1) Home as preferred caregiving place, (2) Factors influencing home care sustainability, (3) Critical decision points for changing places & (4) Challenges in facing death and dying.

These four themes interplayed patterns of caregiving trajectory of frail older persons at the end of life.

Conclusion

The findings revealed important insights of care resources alignment and moral challenges faced by

the family caregivers in sustaining living in place for frail older persons at the end of life. Their voices are explicit. They need to be listened and comforted in facing death and dying of the senior family members.

End-of-life care issues: attitudes of older people living in residential care homes

Ms. Noble LAW P.K.*, C.W.H. CHAN

*Professional Consultant, The Nethersole School of Nursing, The Chinese University of Hong Kong
Volunteer Work for End-of-life Care Services

Objective

To examine the attitudes toward end-of-life (EOL) care issues and preference of place of death in older people living in residential care homes for the elderly (RCHes).

Method

Cross-sectional quantitative study method was used. The attitudes toward EOL issues questionnaire from a UK study was employed and was translated into Hong Kong Chinese version. A structured questionnaire was used to collect the data by face-to-face interview. RCHE older

residents who were cognitively competent with AMT ≥ 6 were recruited.

Results

A total of 150 older people [113 females and 37 males] with an average age of (mean \pm SD) 83.3 ± 7 (range 65 to 96) were included. Results showed that if they were severely ill with no hope of recovery, 86.6% would prefer the doctors to make all the decisions about their care, 65.3% would not want to be kept alive at all costs and 70% preferred to die at the present of family members. In addition, 99.3% of residents perceived RCHes as their own home and 76% actually wished to die in RCHes. Most residents were willing to discuss about EOL care issues during the study.

Conclusion

The results of this study show that many older people wish to spend the last journey of their lives in RCHes because they perceive RCHes as their own home. It advocates the need of providing EOL care services in RCHes in Hong Kong. Knowing the attitudes of older people in RCHes toward EOL care issues is important to meet the challenge of the aging population.

Workshop - Spiritual Care in the End of Life

Dr. Rhoda YUEN

Private Practice

“Spirituality can be defined as the essence of our humanity” (Frankl, 1984). Spirituality therefore is of primary importance in the dying.

The workshop starts with a brief explanation of what terminal patients’ spiritual needs are, how these needs are manifested, as well as direction and goal of spiritual care. Then participants take part in case discussion and exercises to understand how dying patients with spiritual distress are supported and their issues addressed.



Dr. Kitty Wu presenting souvenir to Dr. Rhoda Yuen

Last but not least, participants are taken through practices to prepare themselves to be in tune with how their own spirituality affects their work with the dying.

Dr. Rhoda Yuen facilitating participants to reflect on the spiritual needs of patients



there are moments in life when you are having more questions than answers...

...expecting the unexpected and uncertainties...

managing time as if it is manageable...

...but let's relax



laugh more....



celebrate life....



applause!



The Malaysian cultural dance performance

The conference banquet was held on the evening of the third day in a vibrant atmosphere. The entertainment, the mini showcase of Malaysian cultural dances in Asian fusion music, was enjoyable and fascinating. The evening was brought to a climax when all participants danced with the music after the dinner. With the soaring mood of the delegates, they reached their hands up to get the white and purple balloons as souvenirs – a perfect way to end the evening.



The buzzing conference banquet



The Hong Kong delegates gathered together

Last but not least, Penang is a gourmet's paradise, especially when it comes to hawker's food. Of course, the Hong Kong delegates would not miss this golden opportunity to enjoy the mouth watering Malaysian cuisine in hawker food stalls. Gifted with the tropical climate, Penang is famous for producing fruits like durian, rambuta and duku langsat. Who would care about the few pounds of body weight that we all put on? Yummy!

From all accounts, the conference was a great success. The 10th and the 11th Asia Pacific Hospice Conference will be hosted by Bangkok in 2013 and by Taiwan in 2015 respectively. See you then.



A typical hawker food stall in the street of Malaysia

Palliative Medicine Grand Round

A Palliative Experience with Amyotrophic Lateral Sclerosis

Dr. Mok, Ka Wai Alice, Palliative Care Unit, Shatin Hospital.

Correspondence: mkw474@ha.org.hk

ABSTRACT

Amyotrophic lateral sclerosis (ALS) is a progressive motor neurodegenerative disease. The mainstay of treatment is supportive. An early referral to palliative care is advocated. The anticipated loss of functional capacities in the disease makes advance care planning of particular importance. Options of assistive devices need to be considered. Through the experience of a case, it can be seen that discussions on life-sustaining interventions can be complicated, and the preferences made are subject to change over time. There is sufficient evidence that the quality of life in ALS can be maintained even as the physical function declines.

HKSPM Newsletter 2011 Oct Issue No.2 p25-28.

Case history

Mr. Ho is a 58-year-old male with past history of diabetes mellitus and hypertension. He first presented in late 2009 with an insidious onset of right leg weakness. Signs of right lower limb wasting, fasciculation and brisk reflexes were seen without any sensation involvement. The clinical suspicion of ALS was supported by nerve conduction test / electromyographic studies which showed denervative changes in several muscle groups.

Over the next year, Mr. Ho was followed up at intervals by the Neurology team. His limb power further worsened despite a trial of riluzole. By the end of 2010, his bilateral lower limb power was reduced to grade 0/5 and he was wheelchair bound.

In March 2011, Mr. Ho was admitted via the emergency department for acute respiratory failure due to pneumonia. By that time, he was suffering from dysphonia with prominent wasting of muscles over the chest and four limbs. Non-invasive ventilation (NIV) was started as agreed by Mr. Ho after discussion. However, it was soon noted that he remained NIV-dependent despite the clinical response of his pneumonia to antibiotics therapy. The issue of enteral feeding was also brought up during this admission. Expert opinions from the gastrointestinal endoscopist, anaesthetist, and intensive-care colleagues concluded that Mr. Ho was a high-risk candidate for percutaneous gastrostomy tube insertion. Understanding the risks involved, Mr. Ho decided not to accept the procedure.

Consultation to the Palliative team was made before Mr. Ho was discharged home with the NIV

machine. Home visits were paid to Mr Ho's family. Within the month from his discharge, his weakness progressed further to involve his upper limbs. He was still able to feed on gastric diet, and was tolerating a whole-day use of NIV. He received his care mainly from this wife with the help of a newly employed maid. The overall coping at home was satisfactory although his wife did express some physical fatigue from the constant turning and lifting of Mr. Ho's dependent body.

The issues of future care plan were raised, including the anticipated deterioration in dysphagia and the failure of NIV in support of his respiratory function. Mr. Ho quite readily recalled his previous decision not to take the risk for endoscopy, but would accept the use of nasogastric tube for feeding. Regarding the application of long-term mechanical ventilation, however, Mr. Ho appeared evasive and denied having heard of the option before. It was during one of the later visits that Mr. Ho revealed that this issue of mechanical ventilation had in fact been brought up before during his hospitalization, and it was decided at that time that he would not want a tracheostomy performed. Yet upon revisiting the issue, he remained hesitant.

The palliative team will continue the supportive care for Mr. Ho. It is recognized that ongoing exploration of his wish and preferences will be necessary, for these may subject to change over time and the course of his illness. Psychospiritual support to both Mr. Ho and his carers is also essential, with particular attention to be paid on possible development of depression and carer fatigue.

Timing of referral

The anticipated declining trajectory makes the diagnosis of ALS daunting to most. The treatment for ALS approved at best delayed the progression of disease by a few months. Practical decisions and arrangements on supporting the anticipated losses of body functions have to be made along the course of illness. Our experience with Mr. Ho shows that time is required to establish rapport with the patient and the family in order to facilitate these discussions. An early referral to the palliative team, therefore, will be desirable in the decision-making process.

The European Federation of Neurological Sciences taskforce recommended that a palliative care approach to be adopted early in the diagnosis of amyotrophic lateral sclerosis (ALS), and a referral to hospice or home care teams to be initiated well in advance of the terminal phase of the disease.¹ However, data showed that less than half of the palliative care units in UK provided ALS care, and only <10% of the diagnosed cases had palliative care involvement from the time of diagnosis.²

In the US access to hospice care is subject to more stringent criteria as set by Medicare. The US-based ALS Peer Workgroup³ also suggested the following triggers for hospice referral:

1. FVC 60% predicted (or rapid decline >2% over 2-3 months); or
2. Clinical signs or symptoms of respiratory insufficiency; or
3. Respiratory weakness requiring non-invasive ventilation; or
4. Nutritional decline requiring enteral feeding; or
5. Severe pain or psychosocial distress requiring intensive palliative care interventions (including opioid medication); or
6. Rapidly progressive paralysis (over 2-3 months) in two body regions

Advance care planning in ALS

The predictable decline of mobility, breathing, eating, talking and even thinking – all being the most basic functions one is born with, makes advance care planning (ACP) one of the most important aspects in the palliative care for ALS. The challenges to the palliative team will be not to overwhelm the patients with all the possibilities of the life-threatening conditions, and yet not to delay the discussions till when it is already too late. In this respect, an understanding of the natural history of ALS will be valuable in the timing of broaching these discussions.

Brooks et al⁴ provided some insights on the

trajectories of ALS by studying the different symptoms and functions in 155 bulbar-onset and 547 spinal-onset ALS patients. They found that the segmental spread of symptoms was faster than rostral or caudal spread, and the bulbar symptoms occurred faster in patients with arm rather than leg onset of disease. Swallowing symptoms, on the other hand, occurred earlier following bulbar onset rather than arm/leg onset. Various rates of decline were observed in terms of muscle strength loss, with proximal muscles involved at a later stage than distal groups, and flexor muscles being more affected than extensor muscles. Respiratory failure is the main cause of death in ALS. In this study, a follow-up of the forced vital capacity (FVC) of these patients showed that the FVC in bulbar-onset ALS decreased faster than limb-onset patients.

Ventilatory support

Invasive mechanical ventilation

The application of ventilators is a common consideration in ALS. Some patients may experience an acute respiratory failure against the background of a gradual decline. Others may have previously expressed their wish to receive ventilator support in the event of late-stage pulmonary failure. For some, respiratory failure may be the presenting condition of their disease. While mechanical ventilation may provide the support required to prolong survival, the outcomes of ventilator use will also be worth considering before the start of the device.

Bradley et al⁵ reviewed 24 ALS patients who were intubated within hours of presentation. Among them, 17 had their respiratory failure as the presenting symptom. Only 1 patient was able to be weaned from ventilator support in the end. Sixteen patients required long-term respiratory support with 13 of them being put on invasive positive pressure ventilation via a tracheostomy. The remaining patients died during the admissions. Chadwick et al⁶ reported similar findings in their review of 30 patients. One of them died and 13 failed to wean off the ventilator support. Among the 14 patients who were weaned to non-invasive ventilation, 13 required nocturnal use only.

Although the mean survival of less than a year was reported in the ventilated group^{5,6}, a prolonged survival of up to years can be seen⁷. No predictor can suggest for certain the expected survival before the start of ventilation. In the report by Hayashi⁷, however, over half of the patients who had been using ventilation for over

five years were reduced to either a minimally communicable state or even a totally locked-in state. The author recommended that discussions and planning to maintain effective communication should take place when planned for mechanical ventilation.

Non-invasive ventilation (NIV)

Domiciliary NIV is gaining popularity in recent decades as a means of respiratory support. Its application in ALS not only improves survival⁸⁻¹⁰, but also postpones the start of long term invasive ventilation. Guidelines from the American Academy of Neurology¹¹ suggested the use of NIV for symptomatic hypoventilation. Studies have also supported that NIV slows the decline of pulmonary functions¹²⁻¹³ in tolerant patients, and helps in relieving orthopnea¹³. Improved quality of life was observed, and this improvement persisted despite disease progression^{8,13}. The severity of bulbar weakness is a predictor of tolerance to NIV. Tolerance to NIV, as well as the rate of pulmonary function decline, were found to be the only independent predictors of survival in ALS¹². It is reassuring to see in the study by Mustafa et al⁸ that NIV did not adversely affect the burden or stress experienced by caregivers.

Feeding issues in ALS

Bulbar weakness often manifests as dysarthria and dysphagia in ALS. Dysphagic patients are at risk for inadequate nutrition, resulting in a worsened state of muscle wasting, fatigue and weakness. As dysphagia progresses, enteral feeding should be considered. Percutaneous endoscopic gastrostomy (PEG) is widely used as an alternative or supplemental route for oral feeding.

The American Academy of Neurology practice parameter guidelines¹¹ suggested that the initial management of dysphagia includes the modification of food and fluid consistency, and patients should be followed by a speech therapist. Placement of PEG should be considered in the presence of symptomatic dysphagia with accelerated weight loss, dehydration, or premature ending of meals due to swallowing problems or choking. The timing for PEG insertion should be considered in the context of pulmonary status. Ideally PEG should be inserted before the forced vital capacity (FVC) falls below 50% because the risk of respiratory complications from the procedure increases with the decline in pulmonary function.

Some patients may unfortunately present with

a compromised respiratory status at the time of diagnosis, while others may have undergone a rapid deterioration in pulmonary function before the decision for PEG placement could be made. The use of NIV as an adjunct during PEG insertion had been evaluated for its potential benefit in preventing respiratory complications. Boitano¹⁴ described the successful insertion of PEG with NIV support in all five patients studied. No respiratory complications occurred and these patients were discharged the day after the procedure. Gregory¹⁵ reviewed 33 patients with FVC <50% predicted who attempted PEG placement using NIV. PEGs were successfully placed in all patients, with an oxygenation maintained >88% during the procedure. No significant in-hospital mortality or morbidity was noted. These findings suggested that with the use of NIV, the quality of life and survival benefits of PEG placement may be extended to the group of ALS patients whose respiratory function is already compromised from the disease to a moderate degree.

Percutaneous radiological gastrostomy (PRG), which makes use of fluoroscopic guidance for tube insertion in an air-insufflated stomach, has also been studied for its application in ALS patients with FVC<50%. Chio et al¹⁶ compared the use of PRG versus PEG and found that the decrease in FVC one month after the procedure was significantly less in the PRG group, and the median survival of the PRG group was significantly longer. The authors concluded that PRG was a safe and effective alternative to PEG in patients with moderate or severe respiratory failure.

Patients' choices in ALS

Despite all the advances over the years, ALS remains a disease with poor prognosis without yet a curative treatment. While it is difficult to disclose the diagnosis to patients, it is equally challenging to discuss with them the anticipated course of the disease, and the options of life-sustaining interventions. The timing of such discussions has also been put under question. To make informed choices, patients would require sufficient information and adequate support from the medical team. It is expected that such decisions may change over time with patients' evolving physical and psychological states, as well as an improved understanding with ongoing education and information seeking.

Albert et al¹⁷ undertook a prospective study that assessed patients' preferences for the use of

tracheostomy and PEG placement, and how these preferences early in the disease were related to later treatment choices. Their results showed that only a small proportion of the patients expressed their preferences for the interventions early, but these early preferences predicted their later choices. It was noted that those who found the interventions acceptable were more likely to be recently diagnosed, expressed greater attachment to life, and showed greater declines in pulmonary function over follow-up.

Hope and the future

Riluzole, an inhibitor of presynaptic glutamate release, is currently the only drug with shown efficacy in slowing the progression of ALS. With improving understanding of the pathogenesis underlying ALS, novel targets for intervention have been emerging¹⁸, with some promising studies now entering into the phase 3 trials. Hopefully new therapeutic agents with better efficacy will be available in the near future.

It is reassuring that studies which focused on the quality of life (QOL) of ALS patients similarly showed that their QOL can be maintained. Specifically, Simmons et al¹⁹ found that QOL in these patients did not correlate with physical function, a finding which was further supported by later studies.²⁰⁻²² Psychological, spiritual and social factors all appeared to play a role in determining the QOL in ALS patients.¹⁹⁻²²

These findings underline the importance of palliative care in ALS, suggesting that the attentions of care to be paid not only to the physical side of the patients, but also to the psychospiritual and social aspects of them as well as their caregivers. It can be anticipated that an integrative approach between the neurology and palliative teams shall remain desirable until the day when advances in technology have brought a complete cure to the disease.

References

1. Andersen PM, Borasio GD, Dengler R et al. EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis. EFNS task force on management of amyotrophic lateral sclerosis: guidelines for diagnosing and clinical care of patients and relatives. *Eur J Neurol* 2005; 12(12):921-938.
2. Oliver D, Webb S. The involvement of specialist palliative care in the care of people with motor neuron disease. *Palliat Med* 2000; 14:427-428.
3. Mitsumoto H, Bromberg M, Johnston W et al. Promoting excellence in end-of-life care in ALS. *Amyotrophic Lateral*

- Sclerosis* 2005; 6:145-154.
4. Brooks BR. Natural History of ALS: symptoms, strength, pulmonary function, and disability. *Neurology* 1996; 47:S71-82.
5. Bradley MD, Orrell RW, Clarke J et al. Outcome of ventilatory support for acute respiratory failure in motor neurone disease. *J Neurol Neurosurg Psychiatry* 2002; 72: 752-756.
6. Chadwick R, Nadig V, Oscrift NS, Shneerson JM, Smith IE. Weaning from prolonged invasive ventilation in motor neuron disease: analysis of outcomes and survival. *J Neurol Neurosurg Psychiatry* 2011; 82: 643-645.
7. Hayashi H, Oppenheimer EA. ALS patients on TPPV :Totally locked-in state, neurologic findings and ethical implications. *Neurology* 2003; 61:135-137.
8. Mustafa N, Walsh E, Bryant V et al. The effect of noninvasive ventilation on ALS patients and their caregivers. *Neurology* 2006; 66:1211-1217.
9. Alboussouan LS, Khan SU, Meeker DP, Stelmach K, Mitsumoto H. Effect of noninvasive positive-pressure ventilation on survival in amyotrophic lateral sclerosis. *Ann intern Med* 1997; 127:450-453.
10. Kleopa KA, Sherman M, Neal B, Romano GJ, Heiman-Patterson T. Bipap improves survival and rate of pulmonary function decline in patients with ALS. *J Neurol Sci* 1999; 164:82-88.
11. Miller RG, Rosenberg JA, Gelinas DF et al. Practice parameter: the care of the patient with amyotrophic lateral sclerosis (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology: ALS Practice parameters Task Force. *Neurology* 1999; 52:1311-1323.
12. Coco DL, Marchese S, Pesco MC, Bella VL, Piccoli F, Coco AL. Noninvasive positive-pressure ventilation in ALS – predictors of tolerance and survival. *Neurology* 2006; 67:761-765.
13. Bourke SC, Bullock RE, Williams TL, Shaw PJ, Gibson GJ. Noninvasive ventilation in ALS- indications and effect on quality of life. *Neurology* 2003; 61:171-177.
14. Biotano LJ, Jordan T, Benditt JO. Noninvasive ventilation allows gastrostomy tube placement in patients with advanced ALS. *Neurology* 2001; 56:413-414.
15. Gregory S, Siderowf A, Golaszewski AL, McCluskey L. Gastrostomy insertion in ALS patients with low vital capacity, respiratory support and survival. *Neurology* 2002; 58: 485-487.
16. Chio A, Galletti R, Finocchiaro C, Righi D, Ruffino MA et al. Percutaneous radiological gastrostomy : a safe and effective method of nutritional tube placement in advanced ALS. *J Neurol Neurosurg Psychiatry* 2004; 75: 645-647.
17. Albert SM, Murphy PL, Del Bene ML, Rowland LP. A prospective study of preferences and actual treatment choices in ALS. *Neurology* 1999; 53:278-283.
18. Zinman L, Cudkowicz M. Emerging targets and treatments in amyotrophic lateral sclerosis. *Lancet Neurol* 2011; 10:481-490.
19. Simmons A, Bremer BA, Robbins RA et al. Quality of life in ALS depends on factors other than strength and physical function. *Neurology* 2000; 55:388-392.
20. Robbins RA, Simmons Z, Bremer BA et al. Quality of life in ALS is maintained as physical function declines. *Neurology* 2001; 56:442-444.
21. Chio A, Gauthier A, Montuschi A et al. A cross-sectional study on determinants of quality of life in ALS. *J Neurol Neurosurg Psychiatry* 2004; 75:1597-1601.
22. Matuz T, Birbaumer N, Hautzinger M, Kubler A. Coping with amyotrophic lateral sclerosis: an integrative view. *J Neurol Neurosurg Psychiatry* 2010; 81:893-898.

Palliative Medicine Grand Round

The stress and burden of caregiving

Dr Mansha H. Khemlani,
Palliative Care Unit, Dept. of Medicine & Geriatrics, Caritas Medical Centre.
Correspondence: manshahk@hotmail.com

ABSTRACT

Health and social services rely heavily on family and friends for caregiving at the end-of-life. Caregiving is a challenging experience, with negative consequences for the caregiver. Nonetheless, the experience can be a transformative and meaningful one. With an aging population and declining fertility rates, the burdens of caregiving are on the rise. As health care professionals, we need systems in place to support caregivers, because as a community, we are going to rely on them again and again⁷.

HKSPM Newsletter 2011 Oct Issue No.2 p29-32.

Who or what defines a “caregiver”?

The term “caregiver” is used synonymously with the term “carer”. The Oxford English dictionary defines “carer” as “a family member or paid helper who regularly looks after a child, or a sick, elderly or disabled person”¹. The National Institute of Clinical Excellence (NICE), in their 2004 report ‘Guidance on cancer services improving supportive and palliative care for adults with cancer’, define “caregivers” as “lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management”². However, the definitions of caregiver used in research can be quite diverse. Some research definitions define “caregiver” as “someone most or primarily involved in the patient’s care, or providing most or the majority of the care or assistance”³. Other definitions used in research are based on a minimum task or time commitment e.g. at least 8 hours per day, more than 20 hours per week³.

Caregivers may include people not related by blood or legal ties. They may be geographically dispersed, and not necessarily confined to the same household as the patient. Caregivers may include blood-related family, extended family, friends or even neighbours.

Caregiving tasks

Caregiving is a dynamic process⁴. The burden of caregiving changes with time. There is a marked variation in the range and extent of care provided; the care provided often based on daily judgments by the caregiver of perceived patient need and capabilities^{5,6}.

Caregiving tasks include direct (extrapersonal) care and interpersonal care⁴. Direct care includes management of symptoms and medications, personal care, domestic chores, ambulatory & emotional support provided directly to the patient. Interpersonal care involves partaking in interaction with health care professionals, other relatives and meeting the needs of other family members.

Historically, in caregiving, visible care has been more valued because it tends to be more public, technical and easier to compensate financially than invisible care work. However, caregivers will tell tales of how the care they provided extends beyond the physical and visible.

Visible care includes observable behaviours, including forementioned extrapersonal and interpersonal care. Visible care is, without doubt, time consuming and tiring. However, invisible care requires significant effort and engagement from the carer, and is carried out as a constant surveillance – monitoring and assessment of signs/symptoms, and patient’s energy levels⁶. In contrast to visible care, invisible care is not necessarily associated with observable behavior or with the patient’s knowledge and is often reported as constant, even when the patient is sleeping⁶.

Importance of caregivers in Palliative care

Over the last few decades, developed nations have witnessed significant demographic and social changes³. Demographically, we are seeing an aging population and declining fertility rates.

With an aging population, we are serving more people with chronic progressive illnesses within our health care systems. Socially, we have an increased female labor force and families are geographically dispersed as family units and households become smaller. Elderly, dependant parents are seen geographically dispersed from their only support, their children.

These demographic and social changes come-about at around the same time, when the context in which we provide palliative care is in-itself, undergoing significant changes. Some of the changes we are seeing in the provision of palliative care is an increasing emphasis on home-death and a shift in the focus of care for patients from the hospital to the home⁴. Achievement of death or care at home depends on the availability and willingness of caregivers to provide care. Having a caregiver has been shown to be the single most important predictor of home death⁷.

Caregivers form the very backbone of health and social care delivery³. Both health and social services rely heavily on family and friends for caregiving at the end of life. Without such help, our health and social systems would fail⁷.

Although home death is more an exception than a commonality in our local setting, palliative care still places an emphasis on enabling the patient to live at home for as long as possible⁸.

Caregivers provide a substantial yet hidden contribution to our economy. In the US, caregiver contributions to the economy were estimated to be around US\$ 196 billion annually⁷. In Australia, the contribution of caregivers to the cost of health & social care was estimated annually to be approximately 50% of the total national government's expenditure on health⁷. In the UK, it has been estimated that the overall value of their care is greater than the cost of the National Health Service (NHS).

Caregivers significantly influence both health outcomes and costs in terms of readmission rate and use of inpatient facilities⁹. It is predicted that with recent social and demographic changes, fewer caregivers will be available to provide care and with more people dying with complex care needs, the burdens of caregiving are likely to increase¹⁰.

Mixed impact of caregiving

Caregiving has been shown to have a negative impact in various domains of life for caregivers^{3,4,8,9,11}.



Domain	Examples of impact on caregivers
Physical	Strain, fatigue, sleep deprivation
Psychological/Emotional	Stress, anxiety, depression, helplessness, loss of control
Social	Fewer social contacts, fewer opportunities to socialize
Financial & occupational	Occupational disruption, financial strain
Disrupts daily schedule	Less time available for oneself, presence of fatigue leaves the carer less motivated

The stress and burden of caregiving

Despite the possible negative impact on caregiving, some caregivers were able to appraise the experience as rewarding and/or meaningful³. Caregivers who found the experience meaningful perceived themselves to be healthier than those who saw little/no purpose in the caregiving role⁵.

What is it that “transforms” the stress and burdens of caregiving into a positive experience? Research has shown that caregivers own spirituality helped them find meaning and purpose in their stressful situations, which helped them transcend the demands of caregiving³.

Religious commitment, or viewing themselves as having a relationship with God, self or the environment also helped transform the caregiving experience into a positive one⁵.

Whether the caregiving experience has an overall positive or negative impact on the caregiver depends on the inter-relatedness of the caregiver-patient dyad⁴. For the caregiver, it depends upon the degree of self-efficacy the caregiver feels over a particular experience, the caregivers’ perceived rather than actual capabilities, increased caregiver skill and competence, caregivers’ optimism and positive appraisal⁴. The overall impact on the caregiver also depends upon the patients’ symptoms, distress, immobility and dependency in activities of daily living⁹.

Problems identified by caregivers

Research has shown that caregivers have had to deal with various problems within the health care service, which they hope could have been addressed to help make their caregiving experience a more fulfilling one. Some of the problems include uncoordinated and patchy provision of formal care, lack of a multi-disciplinary team, lack of communication between informal and formal caregivers and lack of communication between formal caregivers

making up the team¹¹. Where there were gaps in the needs & the service provision for cancer patients & their caregivers, the systems in place for non-cancer illnesses were even more deficient.

Caregiver needs

Research on caregivers has shown that they have their own needs, which if addressed, can help make their caregiving experience less stressful and burdensome.

Some of the needs identified by caregivers include^{3,8,9,10,11}

- 
1. Information
 2. Regular access to specialist practitioners
 3. Advice and training on how to fulfill their caring role
 4. Psychological support
 5. Practical help with personal, nursing and medical care of the patient
 6. Domestic help
 7. Financial aid
 8. Out of hours, or night support
 9. Respite
 10. Integrated care service

What can we do to improve caregivers’ caregiving experience?

Caregiving is an experience, which puts significant physical and emotional toll on caregivers. As health care professionals, we must assess caregivers’ physical and mental wellbeing as they commence their roles; and this needs to be assessed on a continuing basis as well. We need to constantly reassess caregivers’ willingness to continue in the caregiving role⁷. We need to distinguish between caregivers who are absolutely unable to take on the caregiving role versus those unwilling to do so.

We should not falsely assume that caregivers will be there when we need them. We need systems in place to support caregivers, because as a community, we are going to rely on them again and again⁷.

To support caregivers, we need to acknowledge the caregivers' role and affirm the importance and inherent difficulties in fulfilling that role. We need to understand the needs of caregivers and the inter-relatedness of the patient-caregiver dyad⁷.

References

1. www.oed.com
2. National Institute for Clinical Excellence (NICE). Guidance on cancer services improving supportive and palliative care for adults with cancer. Oxford: NICE; 2004.
3. Stajduhar K, Funk L, Toye C, et al. Part 1: Home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998-2008). *Palliative Medicine* 2010; 24(6):573-93.
4. Andrews SC. Caregiver burden and symptom distress in people with cancer receiving hospice care. *Oncology Nursing Forum* 2001;28(9): 1469-1474.
5. Carson VB. Spiritual Care: The needs of the caregiver. *Seminars in Oncology Nursing* 1997;13(4): 271-274
6. Clark AM, Reid ME, Morrison CE, et al. The complex nature of informal care in home-based heart failure management. *Journal of Advanced Nursing* 2008;61:373 -383
7. Currow DC, Burns C, Agar M, et al. Palliative caregivers who would not take on the caring role again. *Journal of Pain and Symptom Management* 2011;41(4):661-672
8. Machenzie AE, Holroyd EE. Study of caring and caregiving in Chinese families in Hong Kong. 1st SE Asian Nursing research conference organized by the HK Polytechnic 1994
9. Aranda SK, Hayman-White K. Home Caregivers of the person with advanced cancer. *Cancer Nursing* 2001; 24(4): 300-307
10. Grande G, Stajduhar K, Aoun S, et al. Supporting lay carers in end of life care: current gaps and future priorities. *Palliative Medicine* 2009;23(4):339-344
11. Hasson F, Kernohan WG, McLaughlin M, et al. An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease. *Palliative Medicine* 2010; 24(7):731-736
12. Byock IR. Conceptual Models and the outcomes of caring. *Journal of Pain and Symptom Management* 1999;17(2): 83-92.
13. Holroyd EE. Provision of nursing care for HK families: Future implications. *The Hong Kong Nursing Journal* 1993; 62(6):23-26.

Palliative Medicine Doctors' Meeting

Palliative care of a patient with end stage renal failure and cancer

Dr Bryan Li

Palliative Medical Unit, Grantham Hospital

ABSTRACT

We presented a patient with end stage renal failure on peritoneal dialysis and colon cancer. Pain control in renal failure was discussed. Palliative care needs of renal patients were also discussed.

HKSPM Newsletter 2011 Oct Issue No.2 p33-34

Case history

Ms C, 78 year old woman, was transferred to us for palliative care of colon cancer. Ms C had history of end stage renal failure due to unknown cause, hypertension and hyperlipidaemia. She suffered from ischemic stroke resulted in left hemiparesis.

She was on continuous peritoneal dialysis for ten years already. Initially she performed the fluid exchange herself, but after she suffered from stroke, she was transferred to old age home. Nursing staff in the old age home performed fluid exchanges for her.

Two months ago she presented with upper abdominal pain and new onset anaemia. Subsequent colonoscopy showed adenocarcinoma of proximal colon. CT scan showed liver metastasis and peritoneal lymph node metastasis. After discussion with family and

patient, she did not want any active oncological or surgical treatment.

Her main symptom was right upper quadrant distending dull aching pain related to distension of the liver capsule from hepatomegaly because of liver metastasis. She also had progressive anorexia and weakness, malaise, and nausea with significant cachexia. In the acute ward, the use of tramadol did not achieve optimal pain relief. Our palliative team was consulted and she was transferred to us for further inpatient care with pain and symptom control. She was still on dialysis. Issue of termination of dialysis was discussed, patient and family came to consensus that as the burden of fluid exchange was limited and tolerable to her, and she had been on dialysis for long time without significant complications, they both preferred to continue dialysis. During her stay in our ward, our nursing staff performed the fluid exchange for her and it was uneventful.

Pain control was improved after stepping up the analgesic to methadone. Psychosocial support was offered by nursing staff. Grief and bereavement needs were well attended by medical staff and bereavement counselor. Family grief was supported. Patient finally succumbed after two weeks of stay in our palliative care ward.

Discussion

Pain is a common symptom in the cancer patient and also in patients with end stage renal failure. Pain control is especially complicated among patients with renal failure because of the accumulation of toxic metabolites and hence increased risk of side effects. In a survey about pain in patients with renal failure, musculoskeletal pain was most common (62%), followed by gastrointestinal (13%), and genitourinary (10%)¹.

Pain control in patients with renal failure needs special attention to the pharmacokinetics of the drugs used. For example, morphine is metabolized in the liver to morphine-3-glucuronide (M3G) (55%) and morphine-6-glucuronide (M6G) (10%), nor-morphine (4%) and codeine, all of which are renally excreted. They may accumulate in patients with renal failure. M6G can cross the blood brain barrier, causing central nervous system (CNS) side effects like somnolence and dizziness. Morphine has low protein binding and moderate water solubility, so it is likely to be removed during dialysis. M6G is removed by dialysis but its slow diffusion out of the CNS delays the removal during dialysis.

A recently published review² showed that the half-life of the parent opioid compounds and of their metabolites is increased in the presence of renal dysfunction, for which careful monitoring of the patient, dose reduction and a longer time interval between doses are recommended. Among opioids, morphine and codeine should be used with high caution and possibly avoided in renal failure/dialysis patients; tramadol, hydro-morphine and oxycodone can be used with caution and close patient monitoring, whereas transdermal buprenorphine, methadone and fentanyl appear to be safe to use in patients with renal failure.

Patients with renal failure and dialysis have high palliative care needs.

In a local survey of 179 patients³, 45 patients (25.1%) in the palliative care group and 134 patients (74.9%) in the dialysis group, fatigue, cold aversion, pruritus, lower torso weakness and difficulty in sleeping were the five most prevalent

symptoms in both groups, and were also among the most intense symptoms. Quality of life was significantly impaired in both groups. Scores of all quality of life domains correlated negatively with the number of symptoms ($P < 0.001$). Patients with end stage renal failure under palliative care and dialysis had overlapping symptom prevalence and intensity, significant symptom burden and impaired quality of life.

Actually palliative care needs for cancer patients and patients with non-cancer life limiting illnesses are both significant. This is not just true for renal failure patients, it is also true for other life limiting illnesses. Recent study comparing the illness experience of patients with cancer, heart failure and chronic obstructive pulmonary disease showed that their illness experience depend more on the disease severity, demographic features and emotional and social well-beings⁴. For example, quality of life, depression and anxiety are strongly associated with demographic data like gender, ethnicity and education level rather than disease category.

Advance care planning is important. Advance care planning is the process of discussion between an individual and their health care professionals about future needs⁵. Helping a patient establish their priorities in end of life care enables them to plan their future and prepare for death, allowing them to maintain control over their wants and wishes⁶. This is also important in patients with end stage renal failure. We had discussed the care plan with patient and their family in this case. They chose to continue with dialysis after considering the benefit and burden. We respected their wishes.

References

1. Pham PCT, Toscano E, Pham PMT, et al. Pain management in patients with chronic kidney disease. *NDT Plus* 2009; 2 (2): 111-118.
2. Niscola P, Scaramucci L, Vischini G, Giovannini M, Ferrannini M, Massa P, Tatangelo P, Galletti M, Palumbo R. The use of major analgesics in patients with renal dysfunction. *Curr Drug Targets*. 2010 Jun;11(6):752-8.
3. Yong DS, Kwok AO, Wong DM, Suen MH, Chen WT, Tse DM. Symptom burden and quality of life in end-stage renal disease: a study of 179 patients on dialysis and palliative care. *Palliative Medicine* 2009; 23(2):111-9.
4. Steihauser KE, Arnold RM, Olsen MK et al. Comparing three life limiting diseases: Does diagnosis matter or is sick, sick ? *J Pain Symp Manage* 2011;43(3): 331-341.
5. Royal College of Physicians. Advance care planning. London: RCP, 2009.
6. Davison SN, Torgurund C. The creation of an advance care planning process for patients with ESRD. *Am J Kidney Dis* 2007; 49:27-36.

Palliative Medicine Grand Round

Management of malignant pleural effusion: A brief update

Dr. Poon Yin Clara,
Palliative Care Unit, Caritas Medical Centre.

Correspondence: py213@ha.org.hk

Introduction

Malignant pleural effusion is a common problem encountered in palliative care. The presence of malignant pleural effusion signifies disseminated or advanced disease and limited life expectancy. Median survival ranges from 3 to 12 months.¹ Majority of the patients with malignant pleural effusion are symptomatic. Dyspnoea is the most common presenting symptom followed by chest pain and constitutional symptoms including weight loss, malaise and anorexia. Recurrent malignant pleural effusion significantly impairs function and worsens quality of life of the patients.

The primary therapeutic goal of management is effective palliation of dyspnoea while maintaining quality of life and minimizing hospitalization has equivalent importance. Treatment options are determined by several factors: symptoms, performance status and life expectancy of the patient, the primary tumor type and its response to systemic therapy. Options for management include observation, therapeutic pleural aspiration, intercostal tube drainage and instillation of sclerosant, thoracoscopy and pleurodesis or placement of an indwelling pleural catheter.¹

Management options

Observation

Observation is recommended if the patient is asymptomatic but majority of the patients will become symptomatic and require intervention in due course.

Therapeutic pleural aspiration

For patients who are frail or terminally ill with limited life expectancy (<1 month) and poor performance status, repeated therapeutic pleural aspiration can provide transient symptomatic relief. It should take place under ultrasound guidance and the amount of fluid drained should be limited to 1.5L on a single occasion.¹ However, pleural aspiration alone is associated with high recurrence rate.

Intercostal drainage and intrapleural instillation of sclerosant

Small-bore (10-14 F) chest tube drainage followed by pleurodesis is preferable to recurrent aspiration unless in significant trapped lung. Studies using small-bore catheters with commonly used sclerosants have similar success rates to large-bore catheters while less discomfort is caused.²

Large pleural effusion should be drained in a controlled manner to prevent re-expansion pulmonary edema. On the first occasion, a maximum of 1.5L pleural fluid should be drained while any remaining fluid should be drained 1.5L at a time at 2 hour intervals. Drainage should be stopped if patient develops persistent cough, chest discomfort or vasovagal symptoms.¹

Successful pleurodesis requires satisfactory apposition of parietal and visceral pleura but chemical pleurodesis may still be attempted when complete lung re-expansion or pleural apposition is not achieved, which is due to a dense peel of malignant tissue encasing the visceral pleura. (i.e. trapped lung). However, the amount of trapped lung compatible with successful pleurodesis is unknown. Indwelling pleural catheter may be a better option in the presence of complete lack of pleural apposition. Pleurodesis should not be delayed once the fluid drainage and lung re-expansion is radiographically confirmed while the amount of fluid drained per day before instillation of sclerosant is less relevant for successful pleurodesis.³

There are various sclerosing agents available and the choice will be determined by the efficacy, accessibility, safety, ease of administration and the cost but until now there is no consensus on the optimal agent. Some studies showed that talc is the most effective sclerosant available for pleurodesis.⁴ There are two ways of administration: talc slurry via an intercostal tube or talc poudrage using thoracoscopy. Success rates for talc slurry range from 81% to 100% and thoracoscopic talc poudrage showed equivalent

effectiveness in one large randomized trial.⁵

Common side effects observed with talc slurry include pleuritic chest pain and mild fever but a serious complication associated is adult respiratory distress syndrome (ARDS) or acute pneumonitis leading to acute respiratory failure. Graded talc (particle size >15 µm) should be used to reduce the risk of severe hypoxaemia and ARDS.⁶

Rotation is not required after instillation of sclerosants and the chest tube should be clamped for 1 hour after administration. Removal of chest tube is recommended within 24-48 hours of sclerosant administration in the absence of excessive fluid drainage (>250 ml/day).¹

Thoracoscopy

Thoracoscopy is now widely used in patients with good performance status for the diagnosis of suspected malignant pleural effusion, drainage and pleurodesis. The success rates range from 77% to 100%. Under general anaesthesia, re-inflation of the lung can be visualized which will inform if the lung is indeed trapped and hence guide the decision of pleural catheter insertion or talc poudrage. Pleurodesis can also be successful in partially trapped lung since adhesions preventing re-inflation can be removed.⁷ The most common major complications are empyema, acute respiratory failure and re-expansion pulmonary edema.

Indwelling pleural catheter (IPC)

In patients not suitable for pleurodesis, in trapped lung or with recurrent effusion after pleurodesis, the use of a chronic indwelling tunneled pleural catheter for intermittent fluid drainage is an alternative method for relieving symptoms in malignant pleural effusion. IPC is a fenestrated, silicon catheter with a polyester cuff and a proprietary valve, placed under local anesthesia and connected to a vacuum bottle every few days for drainage of fluid.

Some studies have reported positive results with placement of IPC. A randomized controlled study showed that IPC is an effective treatment for recurrent malignant pleural effusion and requires a shorter hospitalization when compared with doxycycline pleurodesis via an intercostal tube. Besides, it can be managed on an outpatient basis.⁸ The largest series reported on 250 IPC inserted in 223 patients, 88.8% at least achieved partial symptom control.⁹ Another series on 231 patients reported a removal rate of

58% with only 3.8% reaccumulation and 2.2% infection.¹⁰

Therefore, IPCs are being used more frequently for patients in the field of palliative care where the length of hospitalization should be minimized. Though there is a significant cost associated with the devices, there may be cost reduction with a reduced length of hospitalization.

Conclusion

The ideal treatment approach for patient with malignant pleural effusion should offer symptom relief, avoid hospitalization, have minimal side effects or complication and maintain quality of life. There is no clear consensus regarding optimal treatment but the management should be individualized.

References

1. ME Roberts, Edmund Neville, RG Berrisford, et al. Management of a malignant pleural effusion: British Thoracic Society pleural disease guideline 2010. *Thorax* 2010; 65 (Suppl 2)
2. Parulekar W, Di Primio G, Matzinger F, et al. Use of small-bore vs large-bore chest tubes for treatment of malignant pleural effusions. *Chest* 2001; 120: 19-25
3. AG Villanueva, Gray AW Jr, DM Shahian, et al. Efficacy of short term versus long term tube thoracostomy drainage before tetracycline pleurodesis in the treatment of malignant pleural effusions. *Thorax* 1994; 49: 23-5
4. Shaw P, Agarwal R. Pleurodesis for malignant pleural effusions. *Cochrane database systemic review* 2004; (1): 002916
5. Dresler CM, Olak J, Herndon JE, et al. Phase 3 intergroup study of talc poudrage vs talc slurry sclerosis for malignant pleural effusion. *Chest* 2005;127:909-15
6. Janssen JP, Collier G, Astoul P, et al. Safety of pleurodesis with talc poudrage in malignant pleural effusion: a prospective cohort study. *Lancet* 2001;369:1535-9
7. Colt HG. Therapeutic thoracoscopy. *Clin Chest Med* 1998;19:383-94
8. Putnam JB Jr, Walsh GL, Swisher SG, et al. Out-patient management of malignant pleural effusion by a chronic indwelling pleural catheter. *Ann Thorac Surg* 2000;69:369-75
9. Tremblay A, Michaud G. Single centre experience with 250 tunneled pleural catheter insertions for malignant pleural effusion. *Chest* 2006; 129:362-8.
10. Warren WH, Kalimi R, Knodaddian LM, et al. Management of malignant pleural effusion using the Pleurx catheter. *Ann Thorac Surg* 2008;85:1049-55

HKSPM
2010 - 2011



- Chairman
Dr. Kwok Oi Ling, Annie
- Vice-Chairmen
Dr. Lo See Kit, Raymond
Dr. Mak Yi Wood, Yvonne
- Honorary Secretary
Dr. Liu King Yin, Rico
- Honorary Treasurer
Dr. Yuen Kwok Keung
- Council Members
Dr. Sham Mau Kwong, Michael
Dr. Lau Kam Shing
Dr. Chan Kin Sang
Dr. Yau Sau Han, Yvonne
Dr. Tse Man Wah, Doris
Dr. Lam Po Tin
Dr. Lam Wai Man
Dr. Yeung Mei Wan, Rebecca
- Editorial Board
Dr. Tse Man Wah, Doris
(Editor-in-Chief)
Dr. Yeung Mei Wan, Rebecca
Dr. Anne B Thorsen
Dr. Chen Wai Tsan, Tracy
Dr. Lau Kam Shing
Dr. Mansha Hari Khemlani
- Honorary Advisors
Dr. Derek Doyle
Prof. Ilora Finlay
Prof. Sir David Todd
Prof. Rosie Young
Dr. Poon Yuek Foo
Dr. Tse Kin Chuen, Vincent
Dr. Tse Chun Yan
- Honorary Legal Advisor
Gallant Y.T. Ho & Co. Solicitors
- Honorary Accountant
Chu & Chu Certified Accountants

Hong Kong Society of Palliative Medicine Membership Application/Renewal Form

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

Name of institution _____

Title (Dr. Mr. Ms. Mrs. etc) _____ Profession _____

Membership Applied for / Renewed: Full Membership Associate Membership

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)

FOR OFFICIAL USE ONLY

Approved on _____ (date) for Full Membership Associate Membership

Membership fee paid for yr _____ Cheque No _____ Amount _____

Membership Information

Full Member – Any local registered doctors interested in the field; annual fee HK\$150

Member – Other professional workers interested in the field; annual fee HK\$50

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,
c/o Dr. YUEN Kwok Keung,
Dept of Clinical Oncology, Tuen Mun Hospital,
Tsing Chung Koon Road, Tuen Mun, Hong Kong.**

Palliative Medicine Doctors' Meeting (PMDM)

Every 2 months, Tuesday

Multidisciplinary Meeting (MDM)

Every 3 months, Tuesday

Organisers: Hong Kong Society of Palliative Medicine,
Training Subcommittee CC in Palliative Care, HA; Hong Kong Palliative Nursing 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, Chairman, Scientific Subcommittee, HKSPM,
c/o Dept of Medicine & Geriatrics, Shatin Hospital,

Tel 2363 7500 Fax: 2647 7850

Date & Presenting Units

27/9/2011
Tuen Mun Hospital
Caritas Medical Centre

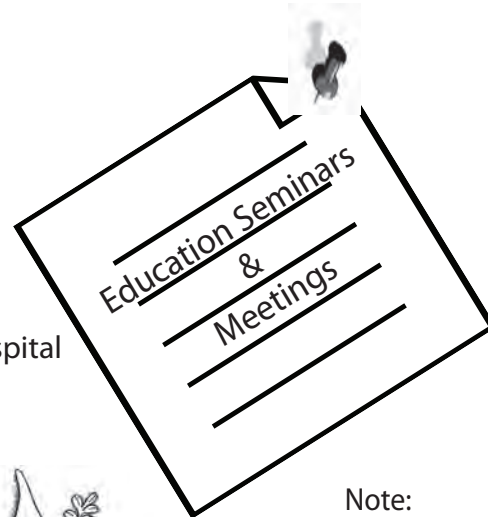
Dec 2011
ANNUAL SCIENTIFIC MEETING

31/1/2012
Queen Mary Hospital
United Christian Hospital

29/3/2012
Pamela Youde Nethersole Eastern Hospital
Haven of Hope Hospital

24/4/2012
Queen Elizabeth Hospital
Our Lady of Maryknoll Hospital

31/7/2012
Prince of Wales Hospital
Ruttonjee and Tang Shiu Kin
Hospitals



Date & Presenting Units

25/10/2011
Queen Mary Hospital
Ruttonjee and Tang Shiu Kin
Hospitals

25/2/2012
Shatin Hospital
Tuen Mun Hospital

26/6/2012
United Christian Hospital
Hong Kong Buddhist Hospital

Note:

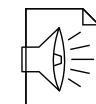
The meeting schedule is based on
the information at time of printing.
Please refer to the latest
announcement for confirmation.



Editorial Board

Dr. Tse Man Wah, Doris
(Editor-in-Chief)

Dr. Yeung Mei Wan, Rebecca
Dr. Anne B Thorsen
Dr. Chen Wai Tsan, Tracy
Dr. Lau Kam Shing
Dr. Mansha Hari Khemlani

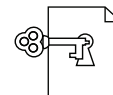


Your suggestions and comments are welcome. Please send to:

Dr. Tse Man Wah, Doris, Chief Editor,
c/o Dept of Medicine & Geriatrics, Caritas Medical Centre,
111, Wing Hong Street, Shamshuipo, Kowloon, HKSAR.
Fax: (852) 2148 4399 E mail: hkspm@fmshk.hk

Disclaimer

Opinions expressed are views of authors and not necessarily
the views or policies of the editorial board or the Hong Kong
Society of Palliative Medicine, the institution with which the
author(s) is/are affiliated, unless it is clearly specified.



Acknowledgment

Our Newsletter is sponsored by
Society for the Promotion of Hospice Care.
Our web is sponsored by Roche.
Please visit our home page:
<http://www.fmshk.com.hk/hkspm>.



Cover photos:
God's hand, Japan,
with courtesy of Dr. Annie Kwok

LATTER LIFE FORUM

晚情論壇 生死兩相安

The Forum entitled "At Ease with Life and Death" was held on 30 July 2011 at the Auditorium of BGCA Building, Wanchai. Dr. Doris Tse (Palliative Medicine Specialist), Ms. Poon Siu Man (Journalist) and Mrs. Yvonne Siu (Media Veteran & SPHC Executive Committee Member) were the sharing speakers. More than 250 people attended with many positive feedbacks.

The first speaker was Dr. Tse who is one of the pioneers in Palliative Medicine in Hong Kong. Inter-weaved her expertise in palliative care, she shared his father's last life journey. In her seemingly simple and factual words of her blog, the audience was touched by the messages she conveyed in an inspiring way. It was felt like a struggle of or juxtaposing a healing doctor, a loving daughter and a caring caregiver supporting the whole family. Audience is thankful for Dr. Tse's heart-warming sharing.

Ms. Poon is an experienced news reporter. She was one of the survivors at the Sichuan Earthquake. She was at Chengdu with her elder sister on 12 May 2008. She shared the incident from her perspective of trying to save her sister who suffered a

life-threatening head trauma from the earthquake. Ms. Poon shared her journey of experiencing post-traumatic stress as well as her reflection and insights towards life. The incident has made her a more caring person and reporter.

Mrs. Yvonne Siu shares her personal insight as a retired professional, and advocates that we need to be proactive to learn about aging, and facing life's inevitable. She has pioneered a Life & Death Education program called 3G Quality Retirement Program at SPHC, targeting retired professionals. Moreover, she shared her learning in this program and the impact on her life. She also highlighted some authors of the Book "At Ease with life & Death II", who shared their unique perspective on life and death. Each participant of the Forum received a copy of the new book.

Photo: Invited speakers answering questions from the floor.



SPHC SPONSORSHIP FOR OVERSEAS PALLIATIVE CARE TRAINING

supported by the TUYF Charitable Fund

The sponsorship is open to medical practitioners, allied health professionals, and others for travelling abroad to engage in study and training in order to gain experience in palliative care. The insights and experience acquired could be adapted locally to enhance the quality of end of life care in Hong Kong. Sponsorship will be open for application twice a year around April and October. This application deadline is 31 October 2011.

Guidelines:

<http://www.hospicecare.org.hk/download/hpc/oversea/guidelines.pdf>

Application form:

http://www.hospicecare.org.hk/download/hpc/oversea/sponsorship_app.pdf

Enquiries

Mr Kwong WU

Tel: 2230 9113 / 2868 1211

Fax: 2530 9320

Email: enrollment@hospicecare.org.hk



Dr. Kwok, another recipient shared her visit to Japan at 8th Hong Kong Palliative care Symposium.



Catherine, sponsorship recipient shared her learning on Narrative Therapy with participants at the Symposium.



Sponsorship recipient, Carol has gained valuable experience in the clinical placement at St. Christopher's Hospice in England.



Attending a group art therapy for patients during Carol's placement.



The mortuary at St. Christopher's Hospice provides a supporting environment for the family to spend time with the deceased.